

# DATA GOVERNANCE COMMITTEE - TERMS OF REFERENCE

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## 1 Purpose

The Data Governance Committee is an external and independent committee established by NPS MedicineWise to provide decisions on the use of data collected by the MedicineInsight program. Decisions to approve uses of data made by the Committee can be implemented by the Executive of NPS MedicineWise at its discretion. Decisions not to approve uses of data will be binding.

## 2 Principles

The Data Governance Committee will operate in accordance with principles that reflect the mission, goals and values of NPS MedicineWise, including commitment to:

- ▷ keeping the consumer at the centre of all our work
- ▷ collaboration, consultation and responsiveness to feedback from stakeholders
- ▷ independent, balanced, accurate and relevant information and education
- ▷ using evidence-based interventions and building the evidence base where gaps exist

## 3 Functions

The key functions of the Data Governance Committee include:

- ▷ To **provide advice** on general data governance issues as and when it is required by NPS MedicineWise. This includes advice relating to ethical, scientific privacy and communication of research applications.
- ▷ To **provide recommendations**, where appropriate, on data access applications.  
Recommendations may be made for purposes such as informing or improving the applicants research project or to suggest specific consumer groups, GPs or researchers for consultation and/or collaboration.
- ▷ To **make decisions** on data access for projects applying for MedicineInsight data. Such decisions will take into account scientific issues, ethical issues and making an assessment of how well the project meets the criteria of public good. Scientific issues for consideration will include clinical, statistical and epidemiological aspects and methodological soundness.

## 4 Reporting

The Data Governance Committee will report to the Chief Executive Officer (CEO) NPS MedicineWise or his/her delegate.

The Chair of the Committee will have the ability to escalate issues directly to the Chief Executive should that be considered necessary.

## 5 Appointment of Chair

The Chair will be appointed, and may be removed, by the Chief Executive.

## 6 Membership

### 6.1 Composition

The Data Governance Committee will have a minimum of 9 and maximum of 14 members. Membership should include:

- ▷ A person with suitable experience and an understanding of general practice data;
- ▷ Clinical general practitioners, including a general practitioner from a practice that is contributing data to MedicineInsight;
- ▷ At least one consumer representative(s) with /experience in research, and an understanding of privacy and ethics;
- ▷ Researcher(s) with expertise in scientific methods, such as epidemiology, biostatistics and observational studies;
- ▷ Individuals with expertise in any one or more of the following:
  - general practice research
  - data linkage
  - public health
  - health policy
  - research and data ethics
  - data privacy considerations
  - data security

### 6.2 Appointment of members

Members are appointed as individuals for their expertise rather than in a representative capacity. Members are appointed by the Chief Executive and may be nominated by the Chair or Research Ethics and Data Governance Specialist in accordance with the Advisory Groups, Editorial Groups and Taskforces Policy. Special provisions apply to the nomination of consumer representatives as set out in that policy.

### 6.3 Succession planning

The Chair and Research Ethics and Data Governance Specialist will be responsible for having a succession plan for the group which will be submitted to the Chief Executive at the end of each calendar year.

### 6.4 Term of appointment

Members are appointed for an initial period of two years, but may be less to stagger appointments to ensure continuity of knowledge of NPS MedicineWise's data governance framework is maintained by the Data Governance Committee. The Chief Executive retains the option to cease this arrangement if circumstances change as set out in the Advisory Groups, Editorial Groups and Taskforces Policy. A member's appointment will only become effective on receipt by NPS MedicineWise of their completed confidentiality agreement and declaration of interest form.

Where a member is regularly unable to attend meetings (e.g. half or more of the years meetings) or to review information and provide advice about projects between meetings, membership will be discontinued unless there are extenuating circumstances as agreed by the Chief Executive.

## 6.5 Reappointment

Reappointment of a member at the end of their initial term will require the approval of the Chief Executive in accordance with the Advisory Groups, Editorial Groups and Taskforces Policy to ensure the member's skills and expertise continue to best meet the needs of the committee and the evolving needs of the organisation. Reappointment will be for a term of two years and subject to the same conditions as the initial term as set out in section 6.4.

## 6.6 Alternates, guests and observers

Individuals are appointed to the committee in their own right and in general there will be no facility for alternates to be appointed. Exceptions may be made upon request to the Research Ethics and Data Governance Specialist and with approval of the Chief Executive.

The Chair may invite guests and observers to attend meetings. Staff attendance in an observer capacity should occur only when this is required for the effective conduct of the meeting and should not hinder the deliberations of the group.

# 7 Roles and responsibilities

Committee members will be required to:

- ▷ Provide advice to the Committee and the MedicineInsight team on matters of scientific validity, ethical appropriateness, acceptability and public good of individual projects and proposals.
- ▷ Review research applications either in committee or electronically within 7 days of receipt.
- ▷ Attend majority of meetings of the Committee.
- ▷ Consider, comment and contribute their individual expertise and judgement where appropriate on all agenda items and make recommendations where further expert input may be required.
- ▷ Assist the Committee to frame clear and unequivocal advice and decisions for NPS MedicineWise by considering the appropriate level of risk and benefit of each application.
- ▷ Develop an understanding of the types and uses of data contained in MedicineInsight.  
Understand how and when the release of data could lead to patients being identified if applications are not scientifically robust.
- ▷ Possess or develop an understanding of Australian medicines regulatory requirements.
- ▷ Treat all matters considered by the Committee in confidence unless otherwise directed.
- ▷ Assess each application on its merits and with impartiality.

# 8 Confidentiality and declarations of interests

All members must comply with the NPS MedicineWise Confidentiality and Declarations of Interests Policy and will be provided with a copy of the policy and associated agreement with their letter of appointment. A member's appointment will only become effective on receipt by NPS MedicineWise of their completed confidentiality and declaration of interest agreement which must be updated annually by members.

## 9 Meeting process

### 9.1 Meeting frequency and location

Meetings will be held every 6-8 weeks or up to six times per year. A meeting may be cancelled if there are no items to discuss, or there is no quorum (a quorum is more than half of the number of Data Governance Committee members).

Meetings will be face to face or by video/teleconference.

### 9.2 Out of Session Meetings

The Data Governance Committee may pass or approve resolutions by circular resolution, including out of session decision making via email.

### 9.3 Notice of meetings

A schedule of meeting dates will be agreed at least 6 months in advance and published on the NPS MedicineWise website.

### 9.4 Meeting papers and minutes

Meeting papers will be despatched at least 7 days prior to the meeting. Late papers will be accepted at the discretion of the Chair.

Minutes will be prepared and circulated to the Chair within 10 days of the meeting. Draft minutes will be distributed to all members within 3 weeks of the meeting.

### 9.5 Correspondence

All external correspondence from the committee, or individual members in their capacity as committee members, must be cleared by the Chief Executive or his/her delegate.

Internal correspondence between the Data Governance Committee and other NPS MedicineWise advisory will be copied to the data governance inbox and Research Ethics and Data Governance Specialist.

### 9.6 Sitting Fees

Members will be paid sitting fees consistent with the prescribed rate set out in the Advisory and Editorial Groups Policy of NPS MedicineWise. This includes reimbursement for travel and accommodation costs for face to face meetings.

## 10 Review of terms of reference

Terms of reference will be reviewed at least once every two years and approved by the Chief Executive.

## Appendix A. Related documents

The following publications are referenced within or govern this procedure. When any of the following publications are superseded, the revision shall apply:

1. Advisory Groups, Editorial Groups and Taskforces Policy
2. Declaration of Interests & Confidentiality Policy for NPS Advisory Groups, Editorial Groups & Taskforces
  - a) NPS MedicineWise Confidentiality Undertaking
  - b) NPS MedicineWise Declaration of Interests Form

## Appendix B. Document control

### Current Version

This classification and other key details of this procedure are listed below:

<b>Title</b>	Data Governance Committee - Terms of Reference
<b>Policy Doc ID</b>	NPS-SOP-016
<b>Security classification</b>	PUBLIC
<b>Document Owner</b>	Research Ethics and Data Governance Specialist
<b>Approving Authority</b>	Chief Executive and Dept of Health
<b>Approval date</b>	31/01/2020
<b>Effective from</b>	31/01/2020

### Changes since last Published Version

The following changes have been made to this procedure since the previous published version:

Version	Date Changed	Date Issued	By Whom	Summary of Changes
1		28/06/16		Initial version
2		21/06/17	Vanessa Halter	Changes to the following sections: Functions, meeting frequency and location, meeting papers and minutes.
		11/11/2019	Lisa Schoenstein Andrew McAlister	Biennial review to update: Function, Composition, Roles and Responsibilities